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Ultimate Survivor Recalls CC Study 65 Years Ago

BY CARLA GARNETT

Leonard Gardner had already survived the "day that will live in infamy." He'd been a signalman aboard the USS Reid when Pearl Harbor was bombed on Dec. 7, 1941. Gardner had lived through battles at Guadalcanal, Okinawa and other significant World War II actions too. Several years past his military service, however, following a routine visit to the doctor, Gardner once again faced imminent mortality—but he didn't know it until many months later.

It was late in 1954. The 33-year-old former sailor and his wife Doris were living in Morningside, a Prince George's County



Leonard and Doris Gardner, in the early days

Md., community developed especially for WWII veterans. The couple—already parents to three young children—was expecting another little one in spring. Still employed by the Navy department, only now as a civilian, Gardner went to his family physician for a checkup.

"I told him I had trouble crossing my legs," recalled Gardner, now a 98-year-old Palmyra, Va., resident along with Doris, now 94. "He immediately poked my legs and determined I had collected a lot of fluid. He told me to get over to the hospital right away. I felt all right, just kinda logy. Apparently, I'd accumulated quite a bit of fluid and didn't realize it."

The doctor sent Gardner immediately to Providence Hospital in northeast Washington, D.C.

"[The doctor] wasn't particularly forthright with me, but he told my wife that it didn't look good and that I probably wasn't going to make it. [He] gave up on me, although he didn't tell me at the time."

Not long after admitting Gardner, Providence discharged him. His condition confounded them and there was nothing more they could do for him.

SEE **GARDNER**, PAGE 6

EARLY EPICENTER

Aberg Offers Clinical Lessons from NYC Frontlines

BY RICH MCMANUS



been some comfort for Covid-19 patients entering Mt. Sinai Hospital (MSH) in New York at the height of the city's pandemic in early April—when

It must have

the 7-hospital medical system was admitting upwards of 2,000 patients a day—to come under the care of Dr. Judith Aberg.

"She knows how to treat patients from

'A DREAM COME TRUE'

Inn Celebrates 30 Years of Helping Patients, Families

BY ERIC BOCK



President, First Lady and HHS secretary open inn.

For the last 30 years, the Children's Inn at NIH has provided a "place like home" for thousands of families whose children undergo treatment at NIH.

"It's wonderful what we—the inn, the NIH and our many supporters—have

SEE ANNIVERSARY, PAGE 8



Seasonal shift? Inn flips the calendar. See p. 12.

ALSO THIS ISSUE

ALSO THIS ISSUE	
Briefs	2
National Academies Ask Experts to E Aging, Environment Interplay	
When a Safety Measure Becomes a F Health Hazard	
Pandemic Project-Palooza	9
Digest	10
Milestones	11
Seen	12

SEE ABERG. PAGE 4

Coleman Award Nominations Are Open

NIMHD announces the 2021 William G. Coleman Jr., Ph.D., Minority Health and Health Disparities Research Innovation Award. Coleman was a distinguished member of the scientific community. He became the first permanent African-American scientific director in the history of the NIH Intramural Research Program (IRP) in January 2011, when he was appointed to direct NIMHD's IRP.



This competitive award program is designed to support 1-year innovative research projects contributed by postdoctoral fellows, staff scientists and staff clinicians within the NIH IRP that have the potential for high impact in any area of minority health and health disparities research.

Preference will be given to candidates under the mentorship of NIMHD intramural or adjunct intramural investigators, although this is not a requirement.

The award will allow up to \$15,000 for supplies and services to be spent by Sept. 10, 2021.

Applications are due by 5 p.m. on Monday, Aug. 31 to NIMHD Coleman Awards at nimhdcolemanawards@mail.nih.gov. Applicants will receive notification of award status by Sept. 30.

For more information, visit https://www.nimhd. nih.gov/programs/intramural/research-award/ research-innovation-award.html.

HEAL Workshop on Myofascial Pain

NCCIH and NIBIB have co-organized an upcoming NIH Helping to End Addiction Long-term (HEAL) Initiative workshop, "Quantitative Evaluation of Myofascial Tissues: Potential Impact for Musculoskeletal Pain Research." This virtual workshop will take place Sept. 16-17 and is free and open to the public.

Myofascial pain syndrome (MPS)—pain originating from muscles and/or associated soft tissues such as fascia—affects an estimated 30 to 85 percent of patients with musculoskeletal pain. Compared with those of the skeletal and central nervous systems, the contributions of myofascial components to this kind of pain are mostly unknown. Many patients with chronic musculoskeletal pain develop side effect issues with opioids, don't respond to surgery, or both. Myofascial tissues are among the last "unturned stones" for research on the tissue types involved in musculoskeletal pain.





NIH Provides Updates on Covid-19 Vaccine

NIH and the biotechnology company Moderna, Inc., provided an update on mRNA-1273, an investigational Covid-19 vaccine, on the morning of July 27. That afternoon, NIH leadership participated in a social media telebriefing on the vaccine, which has now entered phase 3 testing. On hand for the morning session were (above, from I) NIAID director Dr. Anthony Fauci, Operation Warp Speed vaccine lead Dr. Matt Hepburn, and NIH director Dr. Francis Collins. The trial, which will be conducted at U.S. clinical research sites, is expected to enroll approximately 30,000 adult volunteers who do not have Covid-19. Participants in the afternoon session—streamed live on Facebook and conducted at social distance—included Collins (above, r), Fauci (below, r) and Moderna president Dr. Stephen Hoge (not shown). They were joined by special guest Robyn (below, I), a participant in the phase 1 vaccine trial. She helped potential volunteers understand the clinical trials process.

PHOTOS: CHIA-CHI CHARLIE CHANG





The workshop's focus is research and technology opportunities for addressing MPS. Presenters include clinical research experts, imaging and biomechanics experts and computational modelers. In addition to the leads, NIH partners in this trans-NIH meeting are NIAMS, NICHD, NIDCR and NINDS. Registration is required. To register or to view the agenda, visit http://conference.novaresearch.com/MyofascialPain.

'Feds Feed Families' Ends for Summer 2020 with Almost 150 Tons of Food

The Feds Feed Families summer food drive, held annually since 2009, ran this year from June 1 through July 31. The campaign lets federal agencies and staff fight hunger in their communities.

At the drive's summer 2020 close, NIH staff across the country had donated 297,201 pounds of food. HHS as a whole donated 395.655 pounds of food.

Due to Covid-19, the need for food donations has been urgent. The campaign adapted to the social-distancing guidelines and was run entirely online. NIH'ers contributed in several ways: They donated groceries or monetary gifts online, or via a Combined Federal Campaign special solicitation.

Beneficiaries included several organizations with close ties to NIH, including the Children's Inn at NIH and the Safra Family Lodge. For more details on the NIH campaign, visit www.ors.od.nih.gov/FedsFeedFamilies/Pages/default.aspx.

National Academies Ask Experts to Explore Aging, Environment Interplay

BY KELLY LENOX

Environmental exposures that people receive at any age affect how they age, and aging influences the body's response to such exposures. Both aging and disease processes affect the body at multiple levels, from cellular—think chronic inflammation—on up to the whole organism, as when a person becomes disabled.

These interrelationships—and the research needed to clarify them—were the top concerns of experts at a recent virtual workshop sponsored by the National Academies of Sciences, Engineering and Mathematics.



Dr. Michelle Heacock works in the NIEHS Superfund Research Program, which studies health effects of, and clean-up technologies for, chemicals and other substances found at Superfund sites across the country.

PHOTO: STEVE MCCAW

Throughout life, aging and health are influenced by genetics, nutrition and substances or conditions in the environment, according to NIEHS grantee Dr. Gary Miller of Columbia University. "Bridging these disciplines is a logical next step," he said.

One such bridge involves integrating biomarkers of aging with those that reflect relevant exposures,

such as air pollution, heavy metals, arsenic and consumer products. "We need better data to understand how these chemicals intersect," Miller said.

Several discussions during the 2-day event grappled with evaluating exposures to chemical mixtures and interdependent effects of their components.

"Evidence is increasing that early life exposures can impact the risk of disease...long after an exposure has occurred," said NIEHS health scientist administrator Dr. Michelle Heacock. She introduced the idea of individual susceptibility, or that people may respond differently to the same exposure.

"Differential responses can be a function of duration of the exposure, individual genetics, underlying health status, sex differences and timing of exposures," she noted. "We need to consider that exposure burdens can combine with other social determinants of health such as age, gender, education, race and income, which can also affect [a] given individual's response."

Dr. Luigi Ferrucci, scientific director of NIA, agreed. Timing of exposure, especially during sensitive periods of development, is an important consideration.

"When you expose children, you get deficits that last a lifetime," said Dr. Suzanne Fitzpatrick, senior advisor for toxicology at the FDA Center for Food Safety and Applied Nutrition.

In another take on time, Ferrucci described three lenses on aging—biology, clinical symptoms and life functions. He showed how biological changes occur long before function is impaired or clinical symptoms appear. The primary tool we use to measure aging fails to capture this complexity. "We use a watch," he said. "[Yet] chronological age may have nothing to do with health and its trajectory."

"When you expose children, you get deficits that last a lifetime."

~DR. SUZANNE FITZPATRICK

The death of George Floyd at the hands of Minneapolis police officers, as well as the deaths of Ahmaud Arbery, Breonna Taylor and others, was on the minds of participants throughout the workshop, underscoring racial and ethnic health disparities.

Dr. Uchechi Mitchell of the University of Illinois at Chicago described how racial and ethnic disparities in cardiometabolic risk increase with age. "Racism

MENTAL HEALTH

Sandra Howard of HHS

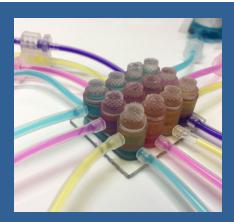
is the primary toxin underlying disparities in cardiometabolic risk and other health outcomes," she said.

"Older persons of color may be particularly impacted because they are more likely to live in socially and economically disadvantaged neighborhoods, and they are less likely to move to

neighborhoods of higher socioeconomic status," Mitchell noted. "Addressing disparities requires an ecological approach." Participants asked how to translate science into immediate action beneficial to vulnerable populations. Community-engaged research is a powerful approach, according to Sandra Howard, from the HHS Office of the Assistant Secretary for Health.

"Communication is important to establish at the beginning, [as you develop] ideas about what it is you want to do," she explained. Howard suggested scientists become familiar with leadership, important issues and other factors and be clear about procedures and protection of confidentiality and health.

Videos of each session are available at https://bit. ly/3gu5MGb.



ON THE COVER: Joint Organ Bioreactor: A bioreactor that is able to generate four microphysiological joint organs (mJoints). Each mJoint has four types of tissues, including bone, cartilage, synovium and fat. They are fed with tissue-specific (top) or universal (bottom) media.

IMAGE: HANG LIN & ROCKY TUAN, UNIVERSITY OF PITTSBURGH

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Aberg

CONTINUED FROM PAGE 1

Ebola, to Zika, to Covid-19," said NIAID clinical director Dr. Cliff Lane, who introduced Aberg's July 8 lecture in the Covid-19 scientific interest group lecture series. "She is an amazing clinical investigator, from HIV to the present time."

"It has really been a devastating time for so many," said Aberg, who is chief of infectious diseases at Icahn School of Medicine at Mt. Sinai and a member of the panel developing NIH Covid-19 treatment guidelines. "The outer boroughs were hit much harder than Manhattan itself...We had 80 deaths per day some days. I am in awe of our frontline providers."

Only 17 percent of the total number of Covid-19 patients admitted to Mt. Sinai Hospital in Manhattan died, she said; 30 percent who were treated in Brooklyn died. "This represents disparities—crowded households, lack of access to health care."

The first U.S. case was reported on Jan. 21. In New York City, the first covid ER admission was on Feb. 29. MSH admitted its first patient on Mar. 7, but by Apr. 9, Mt. Sinai Health System (MSHS) was treating over 2,000 patients daily, which required the erection of medical tents in Central Park and conversion of MSH's lobby into a covid ward made up of patient cubicles.

"The whole hospital pretty much became a covid hospital—essentially ICUs and step-

down units," said Aberg.

"We are down to about 100 patients now," she said, expressing gratitude that the acute phase of the pandemic crested unexpectedly early in her city. "It was overwhelming to see so many individuals as sick as they were."

One case stood out: a man who had been ill at home for 2 weeks before arriving at the hospital with fever, respiratory problems, diarrhea and development of neurological symptoms. He died on the 23rd day of his hospital stay.

"We were not anticipating this," Aberg said. "We

"The outer boroughs were hit much harder than Manhattan itself...We had 80 deaths per day some days. I am in awe of our frontline providers."

-DR. JUDITH ABERG

expected a pneumonia-like disease and treatment requiring ventilators."

Instead they encountered, on the man's autopsy, micro-thrombi, or blood clots in his brain.

"This virus seems to have a predilection for the lining of the blood vessels," she said. "That was a surprise to us...So many times with Covid-19, we are saying 'I don't know."

Aberg's clinical challenges included shortages of PPE (personal protective equipment); at one point she was asked to start Googling for manufacturers that sold hospital-grade masks.

"We always had an adequate number, but brands and types were different, and the staff needed instruction on using them, and fit-testing."

At one point, MSH went to double-bedded intensive care units, "but we were lucky we didn't need split ventilators," Aberg said.

Showing a slide of the ICU, she said caregivers relied on remote monitoring, to keep themselves safe. Tubing in some units ran along floors and under doors, "which is an alarming sight for any infectious disease doctor...It's a very delicate balance between providing care and keeping staff safe."

Relying on advice from China, Italy and other countries hit hard by Covid-19, Aberg drafted clinical treatment guidelines that were modified and approved by a multidisciplinary team. They were updated so frequently that new PDF versions were being published weekly, sometimes daily. Just-intime training sessions also became the norm.

"More than 90 staff from our cancer and medicine clinical trials department were recruited," Aberg recalls. "They helped us roll out studies. There was a tremendous sense of camaraderie. All disciplines were doing everything we could, together."

The first patient they treated with remdesivir survived—a small victory.

On Mar. 19, MSHS launched its first clinical trial. "That usually takes 3 months," Aberg noted.

They got a Regeneron protocol—involving sarilumab, a monoclonal antibody against the interleukin-6 receptor—approved within days.

"That's unprecedented," said Aberg, "that

a clinical trial could open so rapidly."

She said MSHS "jumped on hydroxychloroquine [HCQ], like everybody else in the country," until evidence proved it was ineffective.

"It fell out of favor early, because we saw the harm—QT prolongation in about 8 percent of our patients. I credit the establishment of treatment guidelines leading to improved patient outcomes to the incredible teamwork throughout our system."

On Mar. 28, MSH began convalescent plasma transfusion via an eIND (emergency investigational new drug application) in a cohort of 39 adults



"We really did come together as a faculty," said Aberg. "We're in a much better place now, if we have a second wave."



and 1 child, all of whom received plasma from donors who had high levels of covid antibodies; Aberg had been introduced to the approach during a 2009 NIH-supported study of H1N1 flu treatments.

"By Apr. 17, we were transfusing plasma in all 7 of our hospitals," she said, noting that the therapy is probably most effective when given earlier in the course of illness.

On Apr. 7, a protocol on corticosteroids began when intensivists at Mt. Sinai West found it beneficial. Aberg's colleague Dr. Andy Dunn developed an algorithm to begin anticoagulation therapy in certain patients.

"We had developed a clinical pathway by mid-April," said Aberg, which governed how to treat Covid-19 patients along the spectrum from mild, to moderate, to severe cases.

"We kept simplifying it by changing dense text to graphic figures, making it easier to read and understandable for the teams on the wards," she said.

MSHS also experienced drug shortages, including HCQ and tocilizumab, or "toci."

"Families would come to the security desk at the hospital with vials of toci, but we just could not use them," said Aberg, noting that no chain of custody could be established for these products. A couple brought stem cells, too, in response to newspaper accounts in Israel that they could be effective.

"The sheer volume of patients created a sense of overwhelming hopelessness," said Aberg, who was also frustrated by having to tell families, with fatiguing frequency, that caregivers simply didn't know all the answers.

"That's tough to do with a patient right in front of you who might die," she said.

Other challenges included the consent process—not all patients could do it, Aberg noted. There were briefly worries that the paperwork itself could be a vector of virus transmission.

There were ethical issues involving drugs used for off-label purposes. Sometimes clinical trials were competing for the same patient population.

Then there was the problem of entitlement: people insisting that their loved one is more deserving than another's.

"Everyone is someone to somebody that's true of all patients," Aberg said. "We were faced with so many grievances—we got hit with the anger. It created a lot of discomfort. There was nothing we could do at times. Families and providers were frustrated."

MSHS ended up opening a Center for Stress, Resilience and Personal Growth so that its employees could better manage their stress. "In February, as we were anticipating covid, we activated our emergency management operations center, which remains at a lower level now but prepared and ready to engage as needed for this and any health care crisis," said Aberg. A plasma collection center, too, is opening at MSH later this summer.

In a world where social media reports are frequently unreliable, and scientific preprints are accorded unwarranted authority, Aberg urges the public, "Call us. We can help you sort out what's real and not real. And don't wait to seek medical care—many people stayed home sick, and ended up getting really short of breath before coming in."

At one point, she fielded a call from a person on Long Island who believed that his family ought to ingest crushed chlorine tablets used to sanitize the family pool; another short-lived fad was high-dose ivermectin, used to treat parasites.

Overall, Aberg is heartened by her profession's response to the global pandemic.

"We have many more options now than we had in February and early March—antivirals, immune-based therapies, steroids, anticoagulants...We really did come together as a faculty...We're in a much better place now, if we have a second wave."

During a brief Q&A session, Aberg said that reports of long-term sequelae of Covid-19 infection, including chronic lung disease and cardiac complications, are likely real. "Acute lung injury becomes chronic, acute kidney injury becomes chronic. And I think the neurological complications have been underestimated. We've heard reports of 'brain fog' in people in their 30s and 40s. Some have PTSD after what they've gone through. Many are on home oxygen. We think that about 10 percent of patients may wind up with long-term complications."

She also warned of the upcoming flu season, now only weeks away, where symptoms are going to mimic those of Covid-19.

"We need to be able to test for both," Aberg said, adding that legionella is also a risk now. "We need to brace ourselves."

Tonorezos To Direct Survivorship Office

Dr. Emily Tonorezos has been appointed director of the Office of Cancer Survivorship (OCS) at the National Cancer Institute.

Part of NCI's Division of Cancer Control and Population Sciences, OCS was established in 1996 in recognition of the growing number of cancer survivors and the importance of better understanding and meeting their unique needs. In this position, Tonorezos will lead NCI's efforts to address the challenges facing cancer survivors and their families—to prevent or mitigate adverse effects



Dr. Emily Tonorezos

and to improve the health and well-being of cancer survivors from the time of diagnosis through the remainder of their lives.

"We are very excited to welcome Dr. Tonorezos to the National Cancer Institute," said DCCPS director Dr. Robert Croyle. "NCI is fully committed

to strengthening research on cancer survivors and the OCS director is uniquely positioned to provide key leadership in this important area."

Tonorezos comes to NCI from Memorial Sloan Kettering Cancer Center and the Weill Cornell Medical College, where she served as director of the Adult Long-Term Follow-Up Program for survivors of childhood and young adult cancers. Her research, which has been funded by NIH and by the American Cancer Society, among other organizations, focuses on cardiometabolic consequences of cancer therapy, childhood and young adult cancer survivorship, diet and nutrition and care coordination for this population.

Tonorezos earned her medical degree from the University of Rochester School of Medicine and her master's degree in public health from Johns Hopkins Bloomberg School of Public Health. She completed internal medicine residency and chief residency at Columbia University Medical Center, as well as a general internal medicine fellowship at Johns Hopkins Hospital.

"I'm thrilled that Dr. Tonorezos will be leading our survivorship program," said Croyle. "An exceptional clinician-scientist, she has all of the energy, scientific vision and collaborative skills required to succeed in this challenging role."





In 1955, NIH was celebrating the 25th anniversary of its forerunner, the Hygienic Laboratory, being "renamed, expanded and rededicated in the newly developed health structure," according to the May 31 NIH Record that year. The Clinical Center was just a toddler, having opened in mid-1953. At right, the Gardner family, a few years after Len's participation in a CC study. Below, a page from the 1954 Annual Report of Program Activities describes a CC steroid therapy study.

Gardner

CONTINUED FROM PAGE 1

"I don't think they knew what he had," said Doris. "I don't think they knew what the problem was."

He took extended sick leave from his job. "It was just marking time for me," Len remembered. "I didn't know I was terminal, but my wife did."

About a month later, a coworker called the Gardners at home. She'd learned of Len's illness and wondered whether he ought to try to get examined at NIH. "She was aware of some of the studies they were doing out there and suggested I go be a test patient," I en said

The family doctor wasn't keen on the idea. But after some convincing, he agreed to recommend Gardner to NIH. The Clinical Center admitted Len in January 1955.

Timing was ideal. The hospital had just opened about 18 months earlier. A team at the National Heart Institute, led by principal investigator (and future NHLBI scientific director) Dr. Jack Orloff, was investigating "the effect of steroid therapy in patients with the nephrotic syndrome on renal function and water and electrolyte excretion," according to a 1954 Annual Report of Program Activities published by NIH. Co-PI Dr. Mackenzie Walser, Agnes Preston, Dr. James Baxter and Dr. Howard Goodman, who Gardner remembers, rounded out the research group.

"I became one of the several patients that they had that they were testing for our reaction to a new drug that was being promoted that hadn't been released to the general medical community, but they were experimenting with it and it was called meticorten [prednisone, a corticosteroid]," said Len, who was diagnosed with nephrosis, a kidney disease.

"Only the NIH group identified what the problem was," noted Doris, who, pregnant and with 3 youngsters underfoot, was able to visit Len only once a week. There were no large highways, no Capital Beltway and sparse public transportation from Morningside

the still mostly rural NIH campus back then. Commuting "all the way across town was rather a tedious drive," the Gardners recalled. Also, the hospital didn't allow kids, so Doris had to get a babysitter. As for the CC experience itself, Len said, "There were about 6 or 8 patients there that [the doctors] were playing around with. And I was in there for about 7 to 10 days being monitored.

I remember they'd

I remember they'd come around in the morning—a group of doctors—and they'd poke me in my backbone and they'd poke my legs. They determined that I had so many pounds of fluid in me. After about a week or 10 days, they decided

to put me on this program of meticorten. That was taken by pill. And I'll be darned if it didn't take immediate effect on me. All of a sudden, all my fluids started flowing out...I guess I had a couple of gallons in me. I lost weight so fast! It happened so fast it was just a miracle."

Retired geriatrician Dr. Gordon Margolin,



In recent years, the Gardners, their children and grandkids have gathered for a larger family photo.



who at age 96 volunteers at the Office of NIH History, was a fellow in the kidney disease lab at Boston's Peter Bent Brigham Hospital in the early 1950s. He remembers that cortisone and its derivatives had only recently been found to be "a replenishment for adrenal hormones that were missing in Addison's disease or adrenal insufficiency. Everybody got very excited about the drug. Almost every week at medical grand rounds they'd present a case of some kind of disease that they tried treating with cortisone. It was like a miracle. Almost every week we were seeing cures that we didn't expect. And suddenly this drug, which had just been discovered-or this hormone, which had just been synthesized-became a fantastic and useful therapy for almost everything."

Gardner remembers taking meticorten for about 2 years.

"But not every day," Doris explained.
"Gradually it was reduced, and eventually he was an outpatient for a while. He was in the hospital until May or June, when they finally released him." It was only then that he learned how sick and close to death he had been.

"I was [at NIH] when our child was born, so a neighbor had to take my wife to the



Len Gardner survived the bombing of Pearl Harbor. He served in the Navy as a signalman.

hospital for the birth," Len remembered. "I was out of work for about 6 months."

The life-saving treatments came with side effects as well. "The drug gave me a hump on my back and my breasts blew up," Len recalled. "He got very fat in the face too," Doris added.

There have been no renal issues since Gardner's participation in the study concluded. "The treatment at NIH took care of my kidney problem," he said recently. "I am now 98, almost 99, and have the final stages of COPD."

Gardner's most vibrant memory of his Clinical Center stay, however, is neither the periodic prodding by health care staff, nor the discomfort that often accompanies serious illness nor even the triumph of being a medical research success story. What he chiefly recalls is the tremendous impact the ordeal had on Doris.

"I remember after I got out, my wife really kind of broke down," he said. "It had been such a stress for her. She had been told I was terminal and she was pregnant. She didn't have any idea how she was going to live with 4 children—all of them under 10. She didn't know what her future was."

"Anyway it's turned out okay," concluded Doris, summing up her husband's survival through war and illness. "It's all history now. He was like a cat with 9 lives there for a while. We got very lucky."

When a Safety Measure Becomes a Public Health Hazard

It's clear that wearing masks and face coverings helps save lives. Everywhere we go, in grocery stores, at work, and virtually all public places, the person not wearing a mask often stands out.

You've probably even become accustomed to a routine of washing your face covering or throwing away your surgical mask after returning home. If so, good for you.

NIH has made it even easier to dispose of your face covering if you need to doff it before you leave work. Additional waste receptacles have been placed across all NIH campuses, outside offices, laboratories and inside parking garages. These "step cans" allow a safe, hands-free option for discarding your mask.

Unfortunately, some members of the NIH community are being inconsiderate and not taking advantage of this added convenience. Housekeeping staff and employees alike continue to witness haphazard littering of masks, which makes a public health problem of what is meant to be a safety measure.





Discarded masks, gloves and even a sandwich container mar the stairwell of the MLP-9 parking garage adjacent to Bldg. 10. NIH'ers are urged to use the proper receptacles for all trash, especially during a time of pandemic.

PHOTOS: ELANGOVAN BOOBALAN



NIH is taking extraordinary steps to ensure our facilities are a safe place to work. In addition to the added step cans, increased frequency of waste removal and cleaning of high-touch, high-traffic areas, the Office of Research Facilities will begin more frequent power washing of parking garages on the Bethesda campus. This should help, not only with litter, but also to improve general cleanliness. Ultimately, it still comes down to each individual employee being considerate and ensuring that his or her mask or face covering makes it into a receptacle.

If you need help finding a convenient location, waste management staff has established a waste collection site map (https://nems.nih.gov/Documents/2020%20MPW%20Step%20Can%20Locations. pdf) and comprehensive guide (https://nems.nih.gov/environmental-programs/Pages/Temporary-Changes-in-NIH-Waste-Management-Services.aspx) to all the recent changes related to proper waste disposal at NIH.





Originally, there were 36 patient rooms; 14 years later, the inn opened a new wing featuring an additional 23 rooms. At right, Dr. Philip Pizzo, then dean of Stanford University School of Medicine, and founder of the Children's Inn during his 23-year tenure in NIH's Intramural Research Program, speaks to guests in 2004 at a ceremony in honor of inn expansion.

Anniversary

CONTINUED FROM PAGE 1

achieved together," said inn CEO Jennie Lucca. "Children staying at the inn are true partners in research to the NIH and have helped bring about many new treatments and cures that will benefit children for generations to come."

Since its grand opening on June 21, 1990, the inn has welcomed more than 15,000 seriously ill children; their families have made 60,000 visits. Besides offering a free place to stay during treatment, the inn presents residents with a range of therapeutic, recreational and educational programs and services. The inn also has an emergency fund to help families through tough times; another fund helps families afford therapeutic or academic activities once they return home.

Even though it sits just steps away from the Clinical Center on federal property, the inn is a nonprofit charity supported through private donations. This unique arrangement allows NIH to take care of patients' medical needs while the inn tends to patients' social and emotional needs.

Because of the inn, children from all 50 states and 94 countries have been able to participate in clinical research at NIH. These studies have resulted in successful treatments for children with leukemia and other cancers, HIV/AIDS, serious mental health issues, asthma, bone and growth disorders, life-threatening immune deficiencies, sickle cell disease, periodic fever syndrome and many other rare and serious genetic diseases.

The idea for the inn began in the 1980s, when Dr. Phil Pizzo, then chief of NCI's

Pediatric Branch, began asking about building a house for pediatric patients and their families to stay during treatment. Families back then slept in their cars, local motels or hospital waiting rooms and sometimes ate their meals from vending machines.

Late in that decade, Pizzo met Carmala Walgren, wife of Rep. Doug Walgren (D-PA), through a Clinical Center patient. She learned of the need for a children's home at NIH. With the help of fellow congressional wife Debbie Dingell, wife of Rep. John Dingell (D-MI), congressional leadership and private donations, construction on the inn began shortly thereafter.

"I think what's special about the Children's Inn's history is that people from the NIH, industry, legislators and private citizens came together to make this extraordinary safe haven for seriously ill children and their families a reality," said Lucca.

When the inn first opened, there were 36 rooms for patients, a community room with a stone fireplace, a kitchen and other common areas to encourage interaction among families. In a 1990 interview with the *NIH Record*, inn architect Bob Greenberg explained, "We wanted this house to be an extension of the healing process for kids and families."

The architectural team selected building materials that created a residential feeling, including woodshake shingles, cedar siding, wood planter boxes, copper gutters and downspouts and stone arches. Due to an increase in federal investment in pediatric research, demand for rooms soon outweighed supply. In 2004, the inn opened a new wing featuring 23 rooms, another kitchen and more common areas. Nine years later, the inn opened a playground that appeals across cultures, age groups and physical abilities.

At the inn, 200 regularly scheduled volunteers staff the front desk, tutor, lead activities, help organize in-kind donations and stock community pantries. Over the years, hundreds more have made dinner for families, organized activities and provided other support.

In 2016, the inn began serving residents up to 30 years old. To accommodate their needs, the residence now offers age-appropriate activities and programming. Young adult residents can attend workshops on topics relevant to their age such as family finances, education and career development. The inn regularly offers fun social outings to



President Bush meets with a boy for an impromptu photo session. At the opening, the President said, "The lesson of the inn will show us all that the most important part of life is a very simple one—sharing a laugh, wiping a tear, listening to a loved one."



help young adults network with peers who are experiencing similar challenges.

The inn also began offering adults-only activities for caregivers, while children take part in their own activities. Recently, the inn held a paint-and-sip event, where an instructor led art lessons and the caregivers painted and enjoyed mocktails.

Staff will continue to develop programs and activities that will enhance resident experiences and strengthen communication between the inn and NIH staff. To keep pace with advances in clinical care and technology, the inn plans to renovate resident rooms and common spaces. The renovation will incorporate best practices in hospitality design, communication and infection control. In the next 2 or 3 years, the inn hopes to convert a building across the street into housing for young adults.

At the inn's ribbon-cutting ceremony 30 summers ago, Pizzo declared, "One day the inn will be a monument to the children whose participation in research projects allowed diseases to be cured." He added: "These cures we hope for will allow children to stay in the real inn—their homes."

Three decades later, his prediction continues to ring true.

PANDEMIC PROJECT-PALOOZA What Have You Been Doing With Your Downtime?

There's still time to show off your creative, industrious, constructive—or overly ambitious side! What projects have you been doing during those suddenly scant commuter hours, while we've mostly been in various phases of lockdown? Since the coronavirus pandemic has made telework mandatory for many, the *Record* has been curious to learn what NIH'ers have been up to. Send us a photo and short caption (like the ones here) describing your project by Aug. 24 and we'll make you and your skill/talent/pastime/folly famous (or infamous).



Chez Butler, Now Serving. "I made beef Wellington pot pie (above), a recipe by food writer Allison Robicelli," said Erin Butler of the Office of Communications and Public Liaison, OD. "It uses short ribs instead of tenderloin and it came out as delicious as it looks. I've always wanted to cook with rhubarb, so I made a strawberry rhubarb pie with lattice crust (below). Can't wait for them to come back in season next year."





Butterflies Are Free. "Early during shelter-in-place, my 5-year-old and I cared for 10 butterflies throughout their lifecycle from larva to full-grown Painted Ladies," said Dr. Marrah Lachowicz-Scroggins, program director in the Division of Lung Diseases in NHLBI's Airway Biology and Disease Branch. "Here is the day we released them."



Downsized Lab? "After building four model room kits, I was inspired to design and build my own," said Dr. Alyssa Tonsing-Carter, health science policy analyst in the Clinical and Healthcare Research Policy Division of the NIH Office of Science Policy. "With 3 months of work so far, my laboratory model is still in progress."



Colorized scanning electron micrograph of Neisseria gonorrhoeae bacteria, which causes gonorrhea

PHOTO: NIAID

Rapid Test for Gonorrhea Wins \$19 Million Prize Competition

A diagnostic test capable of accurately and reliably detecting the microorganism that causes gonorrhea, and rapidly determining in under 30 minutes if the microorganism is susceptible to a single-dose antibiotic, is the winner of the Antimicrobial Resistance (AMR) Diagnostic Challenge. Visby Medical, Inc., will receive \$19 million as a prize for its winning diagnostic.

According to the Centers for Disease Control and Prevention, more than 2.8 million antibiotic-resistant infections occur in the United States each year, and more than 35,000 people die as a result. The AMR Diagnostic Challenge is co-sponsored by NIH and the Biomedical Advanced Research and Development Authority (BARDA) of the HHS Office of the Assistant Secretary for Preparedness and Response, with each contributing \$10 million over the course of the competition.

"Antibiotic-resistant bacteria are a growing and concerning public health risk against which we have few effective deterrents," said NIH director Dr. Francis Collins. "Challenge prizes spur innovation and we saw many innovative concepts throughout this competition. I want to congratulate Visby Medical for their winning technology, which could help reduce the unnecessary use of antibiotics, a major driver of antimicrobial resistance."

"One of the challenges health care providers face in combating the growing threat of antimicrobial-resistant infections is identifying which drugs will be effective in treating the initial infection, and fixing that problem starts with rapid, accurate, easy-to-use, point-of-care diagnostics," said BARDA acting director Dr. Gary Disbrow. "Innovative technologies that can rapidly detect and diagnose drug-resistant infections have the potential to measurably improve our response in a public health emergency caused by a drug-resistant pathogen."

The company's diagnostic is a palm-size, single-use, disposable device for the detection of *Neisseria gonorrhoeae*, the microorganism that causes gonorrhea. This diagnostic gives

results quickly, allowing clinicians to treat patients immediately and with the correct medication. Gonorrhea is one of the most frequently seen sexually transmitted infections, which represent a major public health crisis worldwide and in the United States. There were more than 580,000 cases of gonorrhea reported nationwide in 2018 according to the CDC, a 63 percent increase from 2014.

If approved by the FDA, the new device could be useful in ensuring that patients with gonorrhea receive the right antibiotic so that they can immediately begin treatment and will allow other antibiotics to be used for patients with drug-resistant strains of *N. gonorrhoeae*.

New Target for Anti-Malaria Treatments Found

Researchers at NIH and other institutions have discovered another set of pore-like holes, or channels, traversing the membrane-bound sac that encloses the deadliest malaria parasite as it infects red blood cells. The channels enable the transport of lipids—fat-like molecules—between

the blood cell and parasite, *Plasmodium falciparum*. The parasite draws lipids from the cell to sustain its growth and may also secrete other types of lipids to hijack cell functions to meet its needs.

The finding follows an earlier discovery of another set of channels through the membrane enabling the two-way flow of proteins and non-fatty nutrients between the parasite and red blood cells. Together, the discoveries raise the possibility of treatments that block the flow of nutrients to starve the parasite.

The research team was led by Dr. Joshua

Zimmerberg, a senior investigator in NICHD's section on integrative biophysics. The study appears in *Nature Communications*.

In 2018, there were 228 million cases of malaria worldwide, leading to more than 400,000 deaths, 67 percent of which were among children under 5, according to the World Health Organization.

In the current study, researchers determined that the channels through the sac, or vacuole, that encloses the parasite are made of Niemann-Pick

C1-related protein (PfNCR1). The PfNCR1 channels are restricted to locations where the vacuole membrane touches the parasite's membrane. The channels the team discovered in the previous study are formed by exported protein 2 (EXP2). Areas of the vacuole membrane containing EXP2 are located far from the parasite's membrane, at an average distance of 20 to 40 nanometers. The researchers believe that the parasite may use this variation in distance to separate the two transport systems.



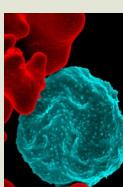
Study Shows Sex Differences in Aspects of Brain Anatomy

A scientific analysis of more than 2,000 brain scans found evidence for highly reproducible sex differences in the volume of certain regions in the human brain. This pattern of sex-based differences in brain volume corresponds with patterns of sex-chromosome gene expression observed in postmortem samples from the brain's cortex, suggesting that sex chromosomes may play a role in the development or maintenance of sex differences in brain anatomy. The study, led by researchers at NIMH, was published in *Proceedings of the National Academy of Sciences*.

"Developing a clearer understanding of sex differences in human brain organization has great importance for how we think about well-established sex differences in cognition, behavior and risk for psychiatric illness," said Dr. Armin Raznahan, study co-author and chief of NIMH's section on developmental neurogenomics. "We were inspired by new findings on sex differences in animal models and wanted to try to close the gap between these animal data and our models of sex differences in the human brain."

Researchers have long observed consistent sexbased differences in subcortical brain structures in mice. Some studies have suggested these anatomical differences are largely due to the effects of sex hormones, lending weight to a "gonad-centric" explanation for sex-based differences in brain development.

However, more recent mouse studies have revealed consistent sex differences in cortical structures as well, and gene-expression data suggest that sex chromosomes may play a role in shaping these anatomical sex differences. Although the mouse brain shares many similarities with the human brain, it is not clear whether these key findings in mice also apply to humans.



Colorized scanning electron micrograph of red blood cell infected with malaria parasites, which are colored blue. The infected cell is in the center of the image. To the left are uninfected cells with a smooth red surface.

PHOTO: NIAI

Dement, Sleep Medicine Pioneer, Dies at 91

Dr. William C. Dement, a physician-scientist widely regarded as the father of sleep medicine, died June 17 at age 91. He had a special relationship with NIH that continued for 30 years. He made numerous discoveries about the health and societal impact of sleep problems—including their link to heart disease and even car accidents—and helped establish the National Center on Sleep Disorders Research (NCSDR), part of the National Heart, Lung, and Blood Institute.

"Bill Dement made unparalleled contributions as a scientist investigating sleep and sleep disorders, as a physician and as an advocate promoting the importance of sleep to health, performance and public safety," said Dr. James Kiley, director of NHLBI's Division of Lung Diseases and a former NCSDR director.

Over the course of his career, Dement was awarded nearly 40 NIH grants for sleep-related research beginning in 1973 and lasting until his retirement in 2003. Among his accomplishments, Dement was awarded a grant by NHLBI to do the first NIH-funded phase 3 clinical trial for sleep apnea, which looked at continuous positive airway pressure (CPAP) therapy for treating the disorder. That trial found that CPAP reduced sleepiness in people with sleep apnea.



Dement, who spent 40 years at Stanford School of Medicine before retiring in 2003, died at a hospital in Stanford, Calif., due to complications from a heart procedure. He was born in Wenatchee, Wash., and later served in the Army during World War

II. After his service, in 1951, he earned a

"Bill Dement made unparalleled contributions as a scientist investigating sleep and sleep disorders, as a physician and as an advocate promoting the importance of sleep to health, performance and public safety."

DR. JAMES KILEY

. . .

Dement received support not only from NHLBI, but also from other institutes for work related to their mission areas, including the National Institute on Aging, the National Institute of Child Health and Human Development, the National Institute of Mental Health and the National Institute of Neurological Disorders and Stroke. His grants included research on sudden infant death syndrome, narcolepsy, hallucinations, insomnia and sleep problems in nursing homes and the elderly.

bachelor's degree from the University of Washington. While earning his degree, Dement—a lifelong jazz enthusiast—hosted jam sessions from his houseboat on Lake Union and played jazz bass, sometimes with famous musicians such as Quincy Jones and Stan Getz.

Dement began his sleep research at the University of Chicago in the 1950s at a time when little was known about sleep or its link to health conditions. In 1953, he discovered rapid-eye movement, or REM sleep, and later showed it was the sleep stage in which dreams occur. He received his medical degree at the university in 1955, followed by a Ph.D. in neurophysiology in 1957. Six years later, Dement moved west to join Stanford University's psychiatry department.

Over the course of his career, Dement would go on to make a number of important discoveries about sleep, including that the sleep cycle had specific phases and that sleep problems could pose hazards such as car crashes and lead to other health issues, too. He linked sleep apnea to cardiovascular problems and speculated that up to 20 percent of the population suffered from the condition, which was later proven to be accurate.

Dement co-authored more than 500 scientific articles and founded the Stanford Sleep Disorders Clinic, the first sleep lab in the United States. He wrote one of the first textbooks on sleep, *Primary Practices of Sleep Medicine*, and was a founding editor of *Sleep*, a prominent journal in the field. He also started the American Sleep Disorders Association, the first major professional organization for sleep researchers, which is now known as the American Academy of Sleep Medicine.

In 1971, Dement created one of the first undergraduate courses on sleep, "Sleep and Dreams," a wildly popular class he continued teaching until about 5 years ago.

Dement helped raise awareness about sleep disorders by appearing on The Tonight Show Starring Johnny Carson and testifying before Congress. His congressional testimony in 1988 helped to create the National Commission on Sleep Disorders Research, which Dement chaired. After Dement's death, Rep. Anna Eshoo (D-CA) honored him on July 13 with a tribute in the House of Representatives recognizing his contributions to sleep research, noting that he was often seen on Capitol Hill in his role as commission chairman. The commission's report, which found that 70 million Americans suffered from sleep problems, spurred Congress to create the NCSDR.

Dement is survived by a son, Dr. Nick Dement; 2 daughters, Elizabeth Dement and Catherine Roos; and 6 grandchildren. Dement's wife of 58 years, Eleanor "Pat" Weber, died in 2014.





At left, Santa Claus, a.k.a. Montgomery County Police Officer Bobby Ladany, greets children and families staying at the inn. At right, Montgomery County Police Officer Charles Wigle watches inn resident Melva open her Christmas in July gifts. Also pictured is Melva's dad, Carlos.

Inn Celebrates 'Christmas in July'

PHOTOS: SONJA LUECKE

On July 22, the Children's Inn at NIH hosted Christmas in July. Santa's motorcycle elves from the Montgomery County Police Department and the NIH Police showered children and young adults, their siblings, parents and caregivers with gifts.

"It was good, thousand times good!" Ujji, 8, from Mongolia said of the first live event held at the inn in months. To keep everyone safe, Santa and his elves wore masks and made sure to physically distance as much as possible.

After a brief stop at the Clinical Center to greet children and young people who are inpatients, Santa returned to the inn to welcome children and families to board buses decorated for the occasion. Escorted by flashing lights and blaring sirens, Santa and his elves guided their guests across the NIH campus, waving to staff they passed along the route.

Back at the inn, Santa and his elves presented gift bags to children, their siblings and family members. The presents, made possible by community members, included toys, insulated cups, Bluetooth speakers, snacks and blankets.

In addition to gifts, children and young adults enjoyed playing in machinemade snow in the July heat and eating a special pizza and salad dinner, followed by a cake to round out the event.

"We are very grateful to NIH and to the Montgomery County Police Department for playing motorcycle elves and bringing joy to our children time after time," said Laura King, head of the inn's volunteer and community outreach. "A special thanks to MCPD Officer Bobby Ladany, who has been our Santa for many, many years, and to the Women for the Inn, who donated meals and dessert. This is such a special, wonderful event for our children and families, especially during this difficult, uncertain time."





Above, Ren, a young adult staying at the inn, and her mom, get ready to enjoy pizza, salad and cake as part of the celebration. At left, twins Julia and Isabella, 3, of Sweden, get their first chance to play in snow in summer—a perfect way to cool off during the heatwave with their mom.